

The **SUPPORT GROUP** is a group level intervention developed in order to help people who are HIV+ understand and learn to live with HIV. The key characteristics of the Support Group are: the creation of a confidential space for people to share their experience of living with HIV; the use of a focus group style first meeting to determine the needs for the support group; the use of facilitators who are members of the target population; the active role of the group participants in the development of the support group and selection of topics; and the experience of “ownership” felt by the support group members.

## CURRENT ACTIVITY SETTING

Medical Center  
HIV Center of Excellence

- ✓ Directly links the client to medical care
- ✓ Gets the client in a conversation about starting medical care
- ✓ Brings the agency closer to where HIV+ people are so that the conversation can begin

## I. Description

### OBJECTIVES

- ▶▶ To educate and provide community support to people living with HIV
- ▶▶ To provide the space that brings together HIV+ people to know each other and end the sense of isolation some people feel
- ▶▶ To facilitate general information exchange about problems and questions relating to HIV, medication, sexuality, family, and community resources
- ▶▶ To connect the content of the support group work with the needs of the participants

### TARGET AUDIENCE

- ▶▶ Native American (seven different tribal nations) and Alaskan Native HIV+ men and women
- ▶▶ Children of adults living with HIV

### ACTIVITY DESCRIPTION

The support group with a focus group is a unique approach to developing a support group for persons living with HIV. Through the use of a pre-support group focus group, agency staff is able to collaborate with persons living with HIV and facilitate the development of a group which addresses very real needs of persons living with HIV.



QUICK NOTES:

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*“When others hear that people are doing well on their medications they give the medications a second chance.”*

— SUPPORT GROUP COORDINATOR, PHOENIX, ARIZONA

Before the support group is formally organized, an initial meeting serves as a “focus group” to chart the real needs the HIV+ community has for a support group. This initial meeting determines the organizational structure and content framework of the support group.

#### **First phase leading to first “focus group meeting”:**

- ▶▶ Case manager receives requests from different clients to start a support project.
- ▶▶ Staff asks other HIV+ clients if they would be interested in participating in a support group and receives affirmative responses.
- ▶▶ Staff asks other departments logistical and developmental questions about their support groups.
- ▶▶ Staff researches internet sources on “starting support groups” and “focus groups” and sets a date, time, and location.
- ▶▶ A location is identified (e.g., a residential or transitional living center). A date and time for the first meeting are set. A space outside of the medical clinic is often desired by the clients for purposes of confidentiality.
- ▶▶ Flyers announce the first meeting of the focus group. “Anyone interested may attend. RSVP. There will be food and refreshments.” The flyer can be posted on bulletin boards in the medical center; case managers can invite their clients to participate in the focus group. Staff can announce the first focus group at planning council meetings and network service providers meetings.
- ▶▶ During the initial focus group meeting, a document is created that outlines the objectives of the support group and the ground rules of confidentiality.
- ▶▶ The objectives are read aloud at the first meeting, which takes place in a conference room around a central table.
- ▶▶ Participants establish a formal name for the group, the frequency of meetings (monthly meetings work well), topics and themes for the group, and how the food provision will be organized (potluck is a popular choice). Usually the group eats first to socialize and then starts the discussion.
- ▶▶ A sign-in sheet for the meeting is helpful to create a confidential internal registry of names and e-mail addresses for sending reminders about future meetings and for quantitative evaluation purposes.

#### **Support group meetings:**

- ▶▶ Case managers select a speaker based on input about needs and interests from the previous meetings.
- ▶▶ A date is chosen (generally the same date each month, e.g., fourth Tuesday of the month from 3p.m. to 4:30 p.m.).
- ▶▶ The speaker, room, and location are all confirmed.
- ▶▶ Notice of the meeting is given orally to clients who have contact with the staff throughout the month and, at one week prior to the meeting, via mail to all active participants.
- ▶▶ This mailing also announces the next support group topic.
- ▶▶ The support group meeting starts with a sign-in and informal introductions while the food is being set out. Participants eat before the meeting “officially” starts. During this social time, the rules of confidentiality are read or stated and the staff is introduced before mingling with participants.
- ▶▶ After eating, there are formal introductions of all of the participants and the invited speaker. Introductions generally include no more than the participant’s name and where they live.
- ▶▶ The speaker presents his or her topic in under 30 minutes leaving time for discussion and questions.
- ▶▶ After the topic discussion, the speaker leaves and the “support group” dynamic begins.
- ▶▶ There is no agenda; the sharing and listening flows naturally. This informal discussion and sharing time is a good opportunity to note potential topics for next month’s meeting. Examples of topics are spirituality, cultural and Native American traditions, nutrition, the HIV lifecycle, “medications in my life,” living with HIV+ and HIV negative partners, and children and HIV.
- ▶▶ Participants may bring family and friends, and with the permission of the group, their adolescent or grown children.

*“It is difficult for many Native Americans to trust in the health care system.”*

— GROUP FACILITATOR, PHOENIX, ARIZONA

- ▶▶ The natural process and evolution of the group may lead it to redefine itself, change courses, or splinter into groups that address the needs of specific populations: teenagers, women, men, etc.
- ▶▶ An oral feedback evaluation is used to close the meeting.
- ▶▶ After the support group meeting is over, the staff conducts an informal discussion about how the group went and discusses the possible content for the next meeting.

## **PROMOTION OF ACTIVITY**

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### **First meeting focus group:**

- ▶▶ Flyers are made to announce the first meeting of the focus group/support group to clients.
- ▶▶ Case managers orally ask clients to participate in the focus group. They also ask other HIV/AIDS service providers to promote it.
- ▶▶ The staff announces the first focus group at planning council meetings and network service providers meetings.

### **Support group meetings:**

- ▶▶ The meeting, time, date, location, agenda, and speaker are posted on notice boards in the medical center, announced orally to regular clients, and sent by e-mail to the clients who signed the registry from the focus group or a previous meeting.

## II. Logistics

### **STAFF REQUIRED**

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- ▶▶ Two case managers

### **TRAINING & SKILLS**

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- ▶▶ The staff must have excellent listening skills, a nonjudgmental attitude, and the time and attention to give to their clients.

### **PLACE OF ACTIVITY**

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A conference room with space and chairs enough for a group of 7 to 20 people

### **FREQUENCY OF ACTIVITY**

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Once a month

### **OUTSIDE CONSULTANTS**

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Guest speakers, or people who come to the meeting to present on a particular topic are often from other AIDS service organizations.

### **SUPPORT SERVICES**

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- ▶▶ Bus tickets, if necessary
- ▶▶ Participant's children are welcome at this particular group.

### **CONDITIONS NECESSARY FOR IMPLEMENTATION**

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- ▶▶ The agency needs to be known and trusted by the community.
- ▶▶ The staff must network with other agencies to identify topics and speakers.
- ▶▶ The support group just “has to be there.” It has to be consistent to build trust among the participants.

## III. Strengths and Difficulties

*“Cultural competency for Native Americans means to know the way of the tribes and be sensitive to the traditions.”*

— SUPPORT GROUP COORDINATOR, PHOENIX, ARIZONA

## **STRENGTHS**

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- ▶ The quality of verbal feedback and sharing among the participants
- ▶ Many participants in the support group greatly appreciate having and participating in a group to share with people from the same culture. Support groups for non-Native American people have low attendance.
- ▶ The participants get a good mental outlook from the group; the program lets the clients know that there are others out there just like them.
- ▶ Clients feel like it is their support group.

## **WEAKNESSES**

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- ▶ Sometimes clients are not willing to open up and participate in the group.
- ▶ The negative attitude of some clients can affect other members of the group.

## **DIFFICULTIES FOR CLIENTS**

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- ▶ Summer is not the best time to plan meetings; heat affects the clients' desire to participate in support groups.
- ▶ Most clients do not have their own means of transportation.
- ▶ Sometimes a client's medical appointment(s) conflict with meeting times.

## **DIFFICULTIES FOR STAFF**

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Unforeseen conflicts or crises sometimes arise that call for immediate creative problem solving by the staff.

## **OBSTACLES FOR IMPLEMENTATION**

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If the program had more funding, it would be easier to provide transportation, which would lead to a better turnout.

## **NON-APPROPRIATE CLIENTS**

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People under the influence of substances, including alcohol. (The group has the right to exclude a person from the meetings.)

# **IV. Outcomes**

## **EVIDENCE OF SUCCESS**

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- ▶ According to the feedback from the doctors who have reported back to the case managers, patients keep appointments with case managers more and ask more questions of their doctors as a result of the support groups.
- ▶ The participants review and discuss the themes and information presented by the invited speakers during the meetings. They earnestly discuss the particular aspects of HIV issues that can be incorporated into their lives: information on treatments, nutritional information, family dynamics and disclosure, and spirituality are only a few of the vital themes addressed in the meetings.
- ▶ Clients generally start out as listeners at first, but quickly become very willing to share.
- ▶ The fact that people come back to the meetings is a clear indicator of success.

## **UNANTICIPATED BENEFITS**

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- ▶ The clients network with each other and share knowledge about resources. People meet in the group and discover that they

live on the same reservation or in the same rural community.

- ▶▶ Clients sometimes begin a natural “mentoring” relationship with one another.

## **“CONNECTING TO CARE” ELEMENTS OF ACTIVITY**

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- ▶▶ When patients hear that others are doing well on medications and hear that other people are okay, they understand in a new way that their health is important and that they have other care options. This can also lead them to give the medications another chance.
- ▶▶ Support group participation makes the client proactive and improves the client-doctor relationship. Staff can facilitate medical case discussions with doctors.
- ▶▶ Identifying common needs and feelings related to HIV infection with other Native Americans can enable a person to make difficult decisions about making appointments at health clinics or beginning treatment.

## **EVALUATION**

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- ▶▶ Using the verbal feedback from the participants, the case managers (facilitators) get a feeling for how their clients feel about the support group, the themes, and the general structure. This feedback dynamic can also reflect the client’s relationship with the larger program: the HIV Center of Excellence and its services.
- ▶▶ The fact that participants bring in friends and family members is an indicator that the meeting space is useful and safe.

## **KEEP IN MIND...**

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- ▶▶ Keeping the groups Native American-specific (or culturally specific) is very important.
- ▶▶ It is important that case managers look like the participants, i.e., the case managers who run the support group should be Native American.
- ▶▶ It’s good to socialize over food and then have a support group discussion.
- ▶▶ The staff has to be very willing to run groups.
- ▶▶ Be consistent and reliable for meeting times and days.
- ▶▶ It could be a good idea to have gender specific groups.

